

"This is not a one year initiative, it's a real journey. As a state and a nation, we are beginning that journey."

Director Ron Levy, Missouri Department of Social Services, discussing the development of a Missouri Health Information Exchange during an August 2009 Regional Listening Session

Overview of Listening Sessions

The 2009 American Recovery and Reinvestment Act (ARRA) provides a unique opportunity for states to access federal funds to plan, design, and implement a health information exchange (HIE) that will encourage the adoption and use of electronic health records (EHRs), and allow for the exchange of health information across institutions and providers.

In August 2009, the Missouri Departments of Social Services (DSS) and Health and Senior Services (DHSS), with the support of Missouri Foundation for Health (MFH) and Health Care Foundation of Greater Kansas City (HCF), organized and executed a series of regional listening sessions to seek stakeholder input regarding the development of a statewide HIE and pursuit of federal funds.

Listening sessions were held in St. Louis, Kansas City, Cape Girardeau, Columbia, Kirksville, and Springfield. The meetings engaged over 200 participants statewide. About half of the participants were health care providers, including hospitals, private providers, federally qualified health centers, rural health clinics, and long-term care providers. Also represented were Missouri health professional associations, insurance companies, academic institutions, foundations, community-based organizations and coalitions, information technology (IT) providers, and state government (legislative and executive). Additionally, representatives from existing regional HIE's participated. A list of participants is available at [website].

At each session, DSS Director Ron Levy and DHSS Director Margaret Donnelly introduced the state's interest in HIE and the process to secure federal funding. The full presentation is available at [website]. Participants then worked in small groups to provide feedback regarding their vision, goals, concerns, and questions about a Missouri HIE. Their feedback fell into several overarching categories:

- Quality Outcomes and Improved Patient Care
- Privacy and Security
- Interoperability and Standardization
- Fiscal Sustainability
- Integration of New Technology
- Stakeholder Engagement (consumers, providers, and policymakers)
- Rural and Urban Needs within a Statewide Model

These regional meetings were an important initial step toward Missouri's development and implementation of a statewide HIE. As the state moves forward in this endeavor, information will be made available here: [website].



Statewide Themes in Discussion

Despite the diversity of the over 200 stakeholder participants, themes arose in response to each discussion question. The following provides a summary of common messages related to each question area. Unabridged notes from each of the six regional meetings are available at [website].

(1) Briefly describe a future vision for a Missouri HIE. What goals should be accomplished as Missouri develops a strategic roadmap for HIT and HIE in the state?

Vision: Participants envisioned a statewide HIE which securely provides access to patient health information to all health providers within Missouri and neighboring states to improve patient outcomes and reduce systemic cost. The system will account for the needs of both patients and providers and engage both sectors in supporting meaningful use of an accessible, fiscally sustainable, and highly secure statewide HIE.

Participants described a roadmap which:

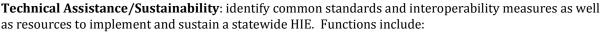
- is driven by a desire to advance the quality of patient care;
- researches and incorporates lessons learned in other HIE regional and state experiences (does not reinvent the wheel);
- educates and engages provider users and patients (permits patient access of EHR);
- accounts for the development and enforcement of strong security and privacy measures;
- builds in strong governance for oversight and accountability measures;
- manages fiscal sustainability at all points in development, implementation, and long term maintenance;
- leverages existing HIT/HIE resources, considers convenience for users (e.g. integration into workflow, time to upload information, secure messaging within a record, etc.), and emphasizes interoperability/standardization;
- provides a timeline for expansion to include all providers, support transactional exchanges (e.g., send orders, make appointments), share images as well as textual data, and connect to state registries (e.g., immunization records);
- addresses who "owns" the data, where it is stored, and how the system is audited; and
- respects different capacities and needs in rural and urban regions of Missouri.

Issues without consensus include whether a federated or centralized model is most appropriate for Missouri's needs, what data should be entered (clinical vs. claims), and if the data should be available for academic or other purposes (e.g., public health trends, workforce planning, etc.).

(2) What roles are critical for a statewide HIE?

Facilitator/Enforcement: provide governance, leadership, and accountability. Functions include:

- maintain a clear timeline, engage diverse and culturally competent constituencies, and keep stakeholders informed of progress;
- develop security and privacy measures and enforce compliance with those standards;
- provide mechanism for consumers and providers to voice concerns;
- generate financial resources and accountability for dollars spent; and
- oversee management of the HIE infrastructure and interoperability capacities as technology advances.



- define and enforce interoperability/standardization measures (intra- and interstate);
- manage affordability and capacity concerns (there was significant discussion about "leveling the playing field" for small and/or rural providers without penalizing other providers' existing investments in HIT and HIE); and
- develop and support implementation of quality assurance and improvement guidelines and statewide goals to improve patient outcomes.

Educator: engage in related research and marketing. Functions include:

- study and disseminate lessons learned from other HIE models; and
- inform and engage consumers, providers, and policymakers in understanding, trusting, and utilizing a statewide HIE.

(3) What are you most concerned about related to HIE?

Participants identified a nuanced set of concerns framed by the overarching concern that a statewide HIE would not be used if various needs were left unmet (cost management, provider utility, public education, etc.). Repeatedly, participants voiced concern about Missouri's capacity to develop resources and momentum necessary to implement a statewide HIE as they envisioned. Broad categories included:

Utilization Concerns

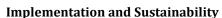
- Will participation be mandated and/or incentivized?
- HIE data entry and retrieval must be integrated efficiently into workflow so as not to be burdensome to providers. How will the generation gap be managed among providers using the system?
- Consumer voices must be included in the process; public understanding of the HIE and protection of patient rights is critical. Who will educate public?
- How will cooperation and trust be fostered between competing providers?

Privacy and Security Concerns

- Who is accountable for maintaining the HIE infrastructure (what happens if it "crashes")? Where is data stored, and who "owns" it?
- How will data integrity be ensured (accuracy/editing, entry and exit from the system, etc.)?
- How will transparency be protected while providing privacy (who is looking at the data and for what purposes)?
- Who will be able to use the data collected and for what purposes? There was concern about how, and if, data should be used to inform public health efforts.

Interoperability and Standards

- Who manages governance and liability issues?
- Who sets the criteria and approves of compliance with the statewide system?
- What data will be used (billing vs. clinical information)?
- What are the metrics for success?
- How will disparate regional systems interact? How will Missouri interface with other states? Will a centralized, federated, or hybrid model be adopted? Participants expressed concern that there might be "islands of interoperability" based on individual health care systems or inconsistent infrastructure which would restrict patient choice and mobility.
- How will existing regional HIE and HIT capacities be integrated with the statewide HIE?
- How will future technological developments be incorporated?



- Who bears the cost of implementation and long term maintenance and expansion? The adoption of HIT may be particularly burdensome for smaller providers.
- How will previous investments in HIT/HIE be accounted for within the new system?
- How will small and/or rural providers be "brought up to speed" to engage in a technologically savvy HIE? How will the HIE account for Missouri's inconsistent internet connectivity?
- Current regional momentum may be lost during this planning phase. Timelines must take care to protect that momentum while being realistic.
- Reimbursement and revenue streams must encourage participation in the HIE.
- Long term sustainability was of great concern. This included funding needs as well as the need to sustain relationships between providers and support of the public.

(4) What general comments do you have related to HIE? What other questions do you have?

Overall, participants expressed enthusiasm for the possible positive benefits for patients through a thoughtfully developed statewide HIE. Comments and questions focused on the common themes of discussion – cost, security, utilization, and interoperability – and included the following additional points:

- Missouri stakeholders must plan and coordinate collectively. To help stakeholders engage with one another, a common set of definitions and terminology should be developed.
- Public accountability and transparency are critical. What communication mechanisms will be used to inform all stakeholders throughout this process?
- There are many levels of "politics" which will impact this process ranging from elected policymakers to provider-provider mistrust.
- Technology changes quickly how will Missouri keep up?
- How will Missouri complete this process with the limited amount of time provided?
- Governance, regulations, and oversight will be difficult.
- What will we do with warehouses of paper documentation? Is it feasible to transcribe decades of paper records into EHRs?
- How do we know the system the state comes up with is going to be better than what we already have?

Next Steps

The statewide Missouri HIE Listening Sessions provided critical information to the state. Overall, participants identified strong potential to improve patient outcomes and reduce cost through effective HIT and HIE in Missouri. During the course of the meetings, guidelines to apply for federal funding were released. The state plans to pursue federal planning dollars and will submit an application for funding in October 2009. As this process evolves, information will be made available here: [website].